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Project Update Issue 4

About CH STRONG

Since 2016, the Centers for Disease Control and Prevention, University of Arizona College of Medicine, University of Arkansas for Medical Sciences, and the March of Dimes have worked together on the Congenital Heart Survey To Recognize Outcomes, Needs, and well-being (CH STRONG), to gather information to help improve the lives of people living with heart defects. We thank everyone who provided information for CH STRONG.

In the last CH STRONG newsletter, we reported that young adults living with heart defects are more likely to report additional comorbidities, such as heart failure, stroke, asthma, and depressive symptoms, than those without heart defects. In addition, only 1 in 10 young adults with severe heart defects or heart failure have an advance care directive, or living will.

On the next page, you will find highlights from a recent publication in the *Journal of the American Heart Association*.



Inside This Issue

"Disability Among Young Adults With Congenital Heart Defects: Congenital Heart Survey to Recognize Outcomes, Needs, and Well-Being 2016-2019" published in *Journal of the American Heart Association*



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Disability Among Young Adults with Heart Defects

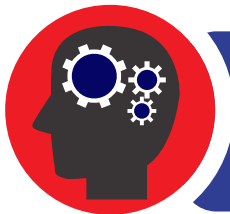
Disabilities are conditions of the body or mind that make it more difficult for the person to do certain activities and interact with the world around them. People with disabilities can lead long, healthy, and productive lives, but may have special healthcare needs and need additional support. Little was known about disabilities among young adults with heart defects.

Therefore, we examined this issue in CH STRONG.

CH STRONG researchers found that



Young adults *with* heart defects are 8 times more likely to have a disability than young adults *without* heart defects.



4 in 10 young adults with heart defects have a disability, with cognitive disabilities the most common type. People with cognitive disabilities may have difficulty concentrating, remembering, or making decisions.



Young adults with a heart defect and at least one disability are more likely to describe themselves as having poor mental or physical health.

Among young adults with heart defects who reported having a disability



5 in 10
were unemployed
in the past year.



5 in 10
had never received
disability benefits.

Visit a heart doctor regularly to prevent or manage problems related to your heart condition and make the best possible choices for your overall health and well-being. If you or a loved one has a disability, ask your doctor about community resources to meet the needs of families and people with disabilities.